

## Test of a Nursing Intervention to Promote Adjustment to Fibromyalgia

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### **Abstract:**

**Purpose:** This was a test to detect whether a 4-week cognitive behavioral nursing program was effective in increasing adjustment to fibromyalgia (FM) and if the treatment effect would last over time.

**Design:** This was a control and treatment group experimental longitudinal study with outcome measures obtained at pretest and every 3 months for 1 year.

**Sample:** A sample of 71 subjects continued their participation throughout the first year of the study.

**Findings:** Treatment subjects had improved posttreatment adjustment and symptom severity compared to control subjects. When subjects with high pretest psychosocial distress ( $n = 5$ ) were removed from the analysis, these findings were statistically significant.

**Implications for Nursing Practice:** The article can provide direction for developing new comprehensive nursing intervention for patients seen with orthopaedic problems. The intervention schedule may help nurses expand their use of interventions for FM patients. Orthopaedic nurses are especially suited for this challenge.

### **Article:**

Fibromyalgia (FM) is a chronic illness characterized by widespread pain with trigger point tenderness, fatigue, and nonrestorative sleep disturbances that are very resistant to treatment (Kaplan et al., 1993). It is estimated that 7–10 million people in the U.S. are affected (Colorado HealthNet, 1996).

Individuals with FM are predominately Caucasian (Wolfe et al., 1996), female (73–88%) (Boissevain & McCain, 1991), and middle aged (age  $x = 49.2$ ) (White et al., 1999). No curative treatment is currently known or available, and yet little is being done to help patients make lifestyle adjustments to manage the illness.

There are a variety of initiating factors for FM such as psychologic distress, sleep disorders (sleep apnea, limb movement disorder), inflammatory bowel syndrome, trauma, and familial tendency. In 51% of their FM respondents (Anderberg et al., 2000), stress from negative life events such as childhood and spousal conflicts as well as economic problems were cited as precipitating causes of the illness and exacerbations. Waylonis and Heck (1992) found some indication that FM may have a genetic basis. They reported that 25% of their FM patients had a parent with FM.

Associated problems seen in individuals with FM include depression, spastic colon, mitral valve prolapse, bursitis, joint pain, constipation, diarrhea, temporal mandibular joint (TMJ) syndrome, and thyroid problems. Additional symptoms include sensory symptoms such as burning and numbness, swollen glands, tinnitus, chronic cough, coccygeal and pelvic pain, tachycardia, and weakness (Waylonis & Heck, 1992). Spasms of the blood vessels in the extremities, irritable bladder and bowel, tension headaches, and sexual problems are also frequently seen with FM (Ng, 1992).

Of the subjects they studied (Waylonis & Heck, 1992), 70% reported that their symptoms were aggravated by increased noise, bright lights, stress, and changes in weather conditions, especially cold temperatures. Symptoms of FM are persistent with 85% of patients indicating significant symptoms and clinical evidence of FM 10 years after the trauma that triggered the FM (Waylonis & Perkins, 1994).

In a 5-year follow-up study, Henriksson (1994) reported that in 50% of the patients, pain, fatigue, and sleep problems increased; less than 20% of the subjects improved; and 30–40% of the subjects reported no change.

A significant problem leading to lost relationships, social isolation, and unemployment is cognitive dysfunction. Slotkoff and Claw (1996) recommend that FM patients should have optimal treatment for FM that focuses on improving FM and the use of compensation techniques to assist memory before cognitive testing.

Neuropsychologic testing reveals cognitive problems with work usage, dyscalculia, concentration, comprehension, sequencing, decision making, visual spatial, fine and gross motor ability, and memory storage and retrieval.

Cote & Moldofsky (1997) noted that FM patients had slower speed of performance than normal and performed more poorly on grammatical reasoning, serial addition/subtraction, and simulated multitask office procedures. Although FM patients performed more poorly than control subjects on tests of immediate and delayed recall and sustained auditory concentration, perceived memory deficits were disproportionately greater than their objective deficits (Grace et al., 1999).

The reviewed studies indicate that FM often becomes a nonremitting syndrome with a variety of physical, social, and psychologic consequences that impair the patients' ability to manage everyday life activities. Due to the chronic nature of FM, nursing interventions are needed to help these individuals adjust to their disease.

### *Treatment Programs for Fibromyalgia*

A number of treatment programs for FM patients have been reported in the literature. These programs can be categorized into four areas: exercise only, education only, behavioral and/or educational programs, and comprehensive treatment programs.

#### **Exercise Programs**

Studies of the effect of exercise in FM patients have focused largely on the premise that regular exercise may benefit the patient by decreasing fatigue and pain, and improving sleep. Mengshoel et al. (1992) conducted a 20-week program consisting of 60-minute exercise twice a week in which subjects failed to demonstrate changes in general pain, pain coping, or fatigue. However, the study emphasized that FM subjects can undergo low-intensity exercise program without experiencing exacerbation of their pain and fatigue.

Likewise, Martin et al. (1996) demonstrated that exercise is beneficial for the management of FM in the short-term and that there were no adverse effects from a program including aerobic exercise, flexibility, and strength training. Although patients reported a perceived benefit with a 6-month fitness program, it failed to produce improvement in physical fitness (Verstappen et al., 1997).

A 12-week exercise program for FM patients conducted by Norregard et al. (1997) had a high number of patients who withdrew from the program, and the program failed to produce improvements in pain, fatigue, general condition, sleep, depression, functional status, muscle strength, or aerobic capacity in any of the treatment groups. Ramsay et al. (2000) conducted a 12-week aerobic exercise program that failed to improve pain control in FM participants, and there was no benefit to having a supervised exercise program over an unsupervised home exercise program.

Two research teams tried combining exercise with biofeedback or psychologic support. Buckelew et al. (1998) combined biofeedback with exercise programs for FM patients but saw no improvement in tender point scores. However, the exercise/biofeedback participants did not show the deterioration demonstrated in the attention group.

Keel et al. (1998) tested a combination of physiotherapy with psychologic support that produced an improvement (3 of 6 parameters) in only 18.5% of the treatment group. These exercise studies together provide little support for the benefit of a structured exercise program with or without biofeedback or psychologic help in improving FM symptoms.

### **Behavioral and/or Educational Treatment Programs**

Several studies have reported on the benefits of behavior and/or educational programs. Following a 6-week program of exercise and education, some patients reported improvements in well-being, walking distance, self-efficacy, knowledge, and fatigue levels at 3 months, but the gains in fatigue and knowledge were lost at 6 months (Gowans et al., 1999).

Participants in an 8-week course of educational/behavioral component, formal relaxation/meditation training, and Qi Gong (Chinese movement therapy) showed improved Fibromyalgia Impact Questionnaire scores, decreased tender points, and increased pain threshold (Creamer et al., 2000).

Nicassio et al. (1997) compared behavioral and educational interventions at 6-month follow-up for the treatment of FM. Although they noted that subjects improved in levels of reported pain and levels of helplessness, there was no difference in the success rates due to type of program.

Likewise, Vlaeyen et al. (1996) reported no advantage in cognitive/ education over the education/discussion group at 12-month follow-up. Goosen et al. (1996) examined FM patients at a 3-year follow-up and concluded that there was no economic justification for the cognitive/education interventions given the higher cost for this type of program as compared to education.

The Arthritis Foundation offers a 6-week educational program aimed at helping individuals adjust to FM. This course has some limitations in that it does not collect outcome data to measure the effectiveness of these programs, it lacks behavioral modification component, and classes are often led by lay people (Personal Communication).

The literature does not support the use of educational programs alone in improving symptom management nor adjustment to FM. For these educational programs to be effective, they must be combined with a more comprehensive approach to the management of FM.

### **Comprehensive Treatment Programs**

Maurizio and Rogers (1997) recommend that while patient education is crucial for the management of FM, the clinician and patient need to identify a more comprehensive combination of treatment options and medications that are most helpful for each patient. Comprehensive treatment programs include medications, exercise, education, psychologic support, and behavior modification. Nielson et al. (1992) reported on a 3-week inpatient cognitive-behavioral treatment program with subjects ( $n = 25$ ) noting less pain severity, emotional distress, anxiety, and depression at discharge.

In another study by Turk et al. (1998a), 67 FM patients participated in a 4-week program of medical, physical, psychologic, and occupational therapies at the University of Washington in Seattle. They reported significant improvements in sense of control, distress, life interference, pain, physical impairment, fatigue, and anxiety at immediate posttreatment measures. At 6 months, patients maintained improvement in pain, life interference, sense of control, distress, and depression.

Bennett (1996) elaborated on the success of the 6-month multidisciplinary University of Oregon Health Science Center (OHSC) program ( $N = 104$ ) with patients demonstrating improved Fibromyalgia Impact Questionnaire scores, improved quality of life, and decreased fatigue on 24-month follow-up data analysis.

The 6-month program includes monthly lectures and monthly support group meetings with individualized exercise, and physical and psychologic interventions as indicated. However, the length of the program, location, and use of a multidisciplinary team (two psychologists, an exercise physiologist, two rheumatologists, and a headache specialist) contribute to the expense of the program. Few patients with FM can afford to relocate to the west coast for 6 months to participate in the program, nor can they afford the cost of such a comprehensive program.

Not all groups of FM patients respond to these treatment programs. Turk et al. (1998b) elaborated on differential responses by psychosocial subgroups of FM patients: dysfunctional (poor coping and high pain), interpersonally distressed, and adaptive copers. Interpersonally

distressed groups responded poorly to treatment. Adaptive copers reported improvements in pain. The dysfunctional group reported significant improvement in pain, distress, perceived disability, and pain interference in their life. The researchers concluded that customizing treatment based on psychosocial profile would lead to enhanced treatment efficacy.

It is notable that the literature in these four areas is mixed but suggests that FM patients can engage in moderate aerobic exercise safely without exacerbation of their symptoms and that a comprehensive plan of management is necessary for this patient population so that they might better adjust physically, emotionally, and socially.

While the exercise and/or education-only programs are cost effective, they are not effective in helping FM patients to manage their illness. The comprehensive programs at Seattle and Portland are more successful but expensive due to the use of multiple specialists. This problem is compounded by the fact that few FM patients have the resources nor the opportunity to relocate for extended periods of time to the west coast for treatment.

### ***Nursing Intervention: Fibromyalgia Rehabilitation Program (FM-REHAB)***

This article reports the results of a nursing intervention program that incorporates the successes of previous work in this area. Most important, the FM REHAB program is unique in that it focuses on the management of the primary symptoms (pain, fatigue, sleep, and cognitive dysfunction) and improvements in sense of control, distress, life interference, physical impairment, and adjustment to FM. The program shares all of the major components with the OHSC program. However, the FM-REHAB program is conducted by a nurse rather than the use of an expensive multidisciplinary team.

The FM-REHAB program meets for 4 consecutive weeks (2 hours/ week on one night) with homework and practice sessions on other days throughout the program. These changes are designed to make the intervention more portable (can be offered at any site) and cost effective.

### **Theoretical Framework**

The theoretical framework for this study is Bandura's (1989) social cognitive theory (SCT) with an emphasis on increasing self-efficacy (SE) for adjustment behaviors. Self-efficacy is Bandura's term for an individual's confidence in being able to perform a given behavior. As SE increases, the likelihood of the individual's successful performance of a specific behavior increases along with the amount of effort and persistence in performing that behavior in the face of obstacles (Bandura, 1982).

For nurses working with clients who have chronic physical disabilities, the client's persistence is essential in learning behavioral changes necessary for better adjustment. In a randomized, controlled trial of a 6-week exercise and education for individuals with fibromyalgia, Gowans et al. (1999) reported improvements in well-being, walking distance, and self-efficacy.

Neerinckx et al. (2000) reported that FM and chronic fatigue patients with symptoms for more than 1 year and who had previous contact with self-help groups had compromised feelings of self-efficacy in dealing with both chronic fatigue syndrome and FM. Just as self-efficacy and

coping strategies affect physical, social, emotional, and role functioning in chronic RA patients (Strahl et al., 2000), this should also be true for FM patients.

Recently, other researchers have linked increased SE expectations with the symptoms and behaviors contained in the FM-REHAB intervention including pain, cognitive dysfunction, fatigue, and exercise behavior. After 4 months in an arthritis self-management course, participants significantly increased arthritis SE scores and decreased pain (Barlow et al., 1999). Participants in Keefe et al.'s (1999) 12-month arthritis treatment program demonstrated higher SE, lower psychologic and physical disability, and pain behavior than the control group. Lackner and Carosella (1999) noted that SE was a better predictor of lifting tasks than either pain control or psychologic distress in patients with low back pain.

Increases in patients' SE for controlling pain and decrease external attributions were found to be essential to successful pain management (Coughlin et al., 2000).

Treatment programs structured around increasing SE have also led to improved memory. Shifren (1999) reported that intellectual functioning related to mental health through SE and pain. Older adults who reported performing poorly on cognitive tasks reported less SE, more pain, and poorer mental health than those who performed well on cognitive tasks. Lowered SE for memory performance was expressed through increased anxiety about memory function, decreased evaluations of memory capacity, and increased perceptions of memory decline (Hood & Bruck, 1997).

McDougall (1998) tested a 4-week nine-session group intervention based on Bandura's SCT. She indicated that increased SE for preventing decline in their memories led to greater use of internal strategy of elaboration, and external strategies of lists and notes. Likewise, a 2-week, 4-session SE group intervention with older adults significantly increased both memory self-efficacy and memory performance in the treatment group (Dellefield & McDougall, 1996).

Self-efficacy expectations have long been linked as one of the strongest predictors of exercise behavior. Frost et al. (2000) reported improved depression, pain self-efficacy, and walking distance at 1 year after participating in a functional restoration program for patients with low back pain. Higher levels of SE correlated with longer distance in ambulation (Moon & Backer, 2000).

Resnick (2000) emphasized that self-efficacy and outcome expectations significantly influenced exercise behavior in older adults. The changes in exercise self-efficacy after treatment significantly related to improvements in fatigue reduction, VO2 max, anxiety, depression, and quality of life in a study of cardiac rehabilitation patients conducted by Jeng and Braun (1997). These studies provide support for the use of SCT in structuring treatment programs for patients with FM.

### ***FM-REHAB Program***

The FM-REHAB program uses the four basic forms of behavior acquisition as proposed by Bandura in his Social Cognitive Theory: role modeling, verbal persuasion, performance

accomplishment, and vicarious experience. The program was designed as a group program so that subjects can use others in the group as positive role models.

Discussions (verbal persuasion) are designed to expose the subjects to methods for modifying their response to FM. Homework assignments allow subjects to use these newly learned behaviors in their everyday life (performance accomplishment) with a discussion of their success in group sessions the following week. The success of the other group members (vicarious experience) encourages other subjects to try the new adjustment behaviors.

Components of the FM-REHAB program were developed using a review of the literature, two panels of experts (nurses and patients), and the principal investigator's experience in dealing with chronic illness for 30 years. The nursing intervention was designed to teach individuals with FM about the disease, symptom management (pain, fatigue, sleep, and cognitive dysfunction) and self-care behaviors.

Behavioral components include medication use, improved communication with their health care provider, stretching and exercise, energy conservation, diet and nutritional supplements, sleep hygiene, responding to others' reactions to their FM, and cognitive retraining.

Additionally, stress reduction activities (progressive muscle relaxation and guided visual imagery) are included in the FM-REHAB program as the literature demonstrated that the use of a stress reduction program resulted in improved well-being, pain levels, sleep, and fatigue levels in 51% of FM subjects (Kaplan et al., 1993).

It is hypothesized that the increased use of self-care behaviors will improve symptom management leading to improved adjustment, improved well-being, and increased activities (see Figure 1).

**FIGURE 1**  
**Proposed Model**

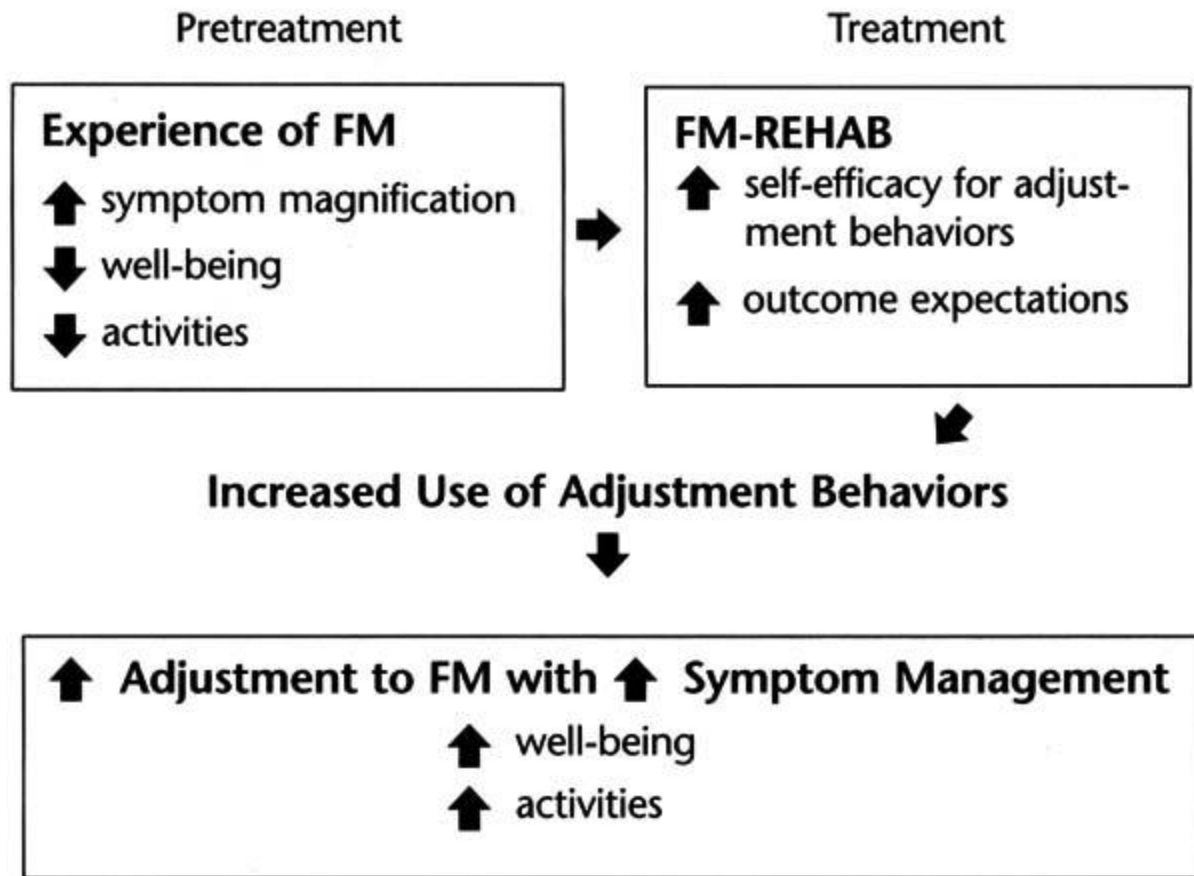


Figure 1 Proposed Model

### *FM-REHAB Program Content*

#### **Pain Control and Medication Management**

Pain control in FM is approached from both a behavioral and medication management perspective. The expected outcomes are for participants to (1) be aware of recommended medications and doses of drugs used to manage pain, (2) facilitate self-management, and (3) facilitate discussion of disease management with their health care provider. They are given medication sheets to take to their health care provider listing recommended medications and dosage ranges as recommended by the Colorado Health Network (2000).

Subjects are taught that antidepressants (Elavil, Flexeril, Sinequin, Xanax, Tranzone, Klonopin or Pamelor) are prescribed to decrease pain and promote sleep. The efficacy of pain medications such as aspirin, Tylenol, and NSAIDs, especially for patients with arthritis, are discussed. It is suggested that stronger narcotic medications (Codeine, Vicodin, Darvon, and Ultram) should be reserved for severe “break-through” pain. Serotonin-boosting medications (Prozac, Paxil, Zolof, Serzone, and Efflexor) are suggested for decreasing cognitive dysfunction and fatigue. Flexeril



and Norflex may be useful in decreasing muscle spasms. Medications for irritable bladder (Ditropan) or irritable bowel (Butibel and Librax) are also discussed.

The use of uricosuric drugs (Robinul, Guaifenesin) are mentioned because many of the patients have misperceptions regarding the efficacy of these drugs that require considerable diet and health care product restrictions. Drug brand names are used because this is less confusing for the participants.

Behaviorally, participants are taught nonpharmacologic pain management strategies and communication skills to advocate for themselves when dealing with their health care provider. Rest, massage, exercise, stretching, heat, and cold are all nonpharmacologic modalities for managing pain. They are also given a list of health care providers in their area who have been recommended by other participants.

### **Fatigue**

Energy conservation and good nutrition are essential in dealing with fatigue associated with FM. Treatment subjects are taught to pace their activities daily and weekly, balance rest and activity, and to seek early treatment for medical problems using “body listening” (cue recognition) for early signs of trouble. They learn to budget their limited energy resources much as they do their checkbook. Subjects examine activities that could be eliminated, redesigned, or delegated to others.

### **Diet and Use of Dietary Supplements**

Following instruction on the food pyramid, participants are encouraged to eat a well-balanced diet. Because many FM patients have multiple chemical sensitivities and allergies, subjects are taught how to identify and avoid food allergies as much as possible. For irritable bowel syndrome, increase roughage consumption is recommended. Supplements with research support (Werbach, 2000) for FM symptom management include Vitamin B complex (improved nerve cell and immune functioning, decrease fatigue and depression), Vitamin C (increase immune and microcirculation functioning), magnesium and malic acid (decrease muscle pain), and zinc (increased immune functioning, muscle strength, and endurance; decrease pain and fatigue).

Titrated doses of these supplements follow Werbach's (2000) guidelines. Mountz et al. (1995) reported decreased regional cerebral blood flow in FM patients. Because Ginkgo helps to increase cerebral blood flow, it is recommended. They are also cautioned to avoid excessive use of untested supplements and to watch for overdosing on supplements.

### **Sleep Promotion**

Sleep promotion is another key area that is covered. Cote and Moldofsky (1997) noted that FM patients spent more time in stage 1 sleep and reported more problems with sleepiness, fatigue, pain, and negative mood than controls.

Subjects learn the need to engage in regularly scheduled, moderate exercise and stretching, practice environmental control and good sleep hygiene, and have regular sleep hours even on the weekend. They are also cautioned to watch the effect of naps on their sleep. Tricyclic antidepressants are recommended to promote sleep along with a skeletal muscle relaxant such as

cyclobenzaprine HCL (Flexeril). The use of sleeping pills and hypnotics should be restricted to very short periods.

### **Stress Management**

Anderberg et al. (2000) provides evidence for stress being a causative factor in the development and exacerbation of FM. Unusual life stress frequently occurs in the period preceding increased symptoms. Stress management techniques (guided visual imagery and progressive muscle relaxation) are an integral part of the FM-REHAB program. Psychosocial issues that cause stress are covered, including role changes, need for social support, decision-making, prioritizing activities, and handling the reactions of others/self to FM disabilities. Employment, social security, vocational rehabilitation, disability compensation, support groups, and helpful agencies are discussed.

### **Cognitive Dysfunction**

This is an area that is not reported as part of the comprehensive programs in the literature. The FM-REHAB Program teaches methods for decreasing the impact of cognitive dysfunction on subjects' lives. The serotonin increasing drugs, such as fluoxetine (Prozac), are useful for increasing low serotonin levels seen in FM patients.

Increased serotonin levels will decrease fatigue and increase alertness. Participants are taught that decisions should not be made when the patient is fatigued, and they should break tasks into the smallest components that can be achieved sequentially without distractions. Even though they think that they may remember an important piece of information or directions, participants are encouraged to write down this material.

Subjects are also given suggestions for cueing their memory such as post-it-notes, rehearsal, and repetition. Cognitive games such as jigsaw and crossword puzzles are suggested as helpful activities for stimulating memory. Suggestions for transportation, reading, coping with the medical maze and lifestyle management are also covered. (See Table 1 for Program Schedule.)

**TABLE 1**  
**Treatment Session Content and Homework**

### WEEK 1

#### Discuss

1. The disease process of FM
2. Factors influencing FM & past experiences
3. Affects of extremes in hot and cold and infection
4. Reinforce need to stretch and exercise daily
5. Medications used to help manage FM symptoms
6. How to communicate with health care providers

#### Behavior Training (Teach and practice)

1. Head to toe stretching exercises
2. Progressive muscle relaxation (PMR)

#### Homework

1. Keep a journal of all activities for week
2. Keep a 3 day diet recall
3. Use PMR daily

### WEEK 2

#### Discuss

1. Reports on effects of using PMR
2. Review of three day diet recall, Teach four food groups and amounts, address helpful diet supplement and warn about abuse of over the counter substances
3. Relationship between fatigue, pacing, balance of rest and activity, and energy conservation
4. Need for appropriate and regular exercise

#### Behavior Training

1. Head to toe stretching exercises
2. Guided visual imagery (GVI)

#### Homework

1. Practice imagery daily
2. Use energy conservation principles.
3. Eat a well balanced diet
4. List factors (+/-) shaping reaction to

### WEEK 3

#### Discuss

1. Psychosocial influences on FM (role changes, support network, decision-making, and prioritizing activities)
2. Handling reactions of others/self to FM symptoms
3. Employment issues and & sources of help (social security, vocational rehabilitation, and support groups and agencies)
4. Sleep promotion and good sleep hygiene

#### Behavior Training

1. Head to toe stretching
2. Low-impact exercises

#### Homework

1. Note times when cognitive dysfunction (CD) is most problematic
2. Track methods used to control CD

### WEEK 4

#### Discuss

1. Memory and information storage
2. Effects of cognitive dysfunction (CD) on life
3. Ways to help decrease the impact of CD on life

#### Behavior Training

Use methods taught to control their symptoms and live a more healthy life

#### Homework

1. Keep track of use of adjustment behaviors on patient flow sheet
2. Return questionnaires in a timely manner
3. Notify the researcher of any address change
4. Contact the researcher by phone for needed assistance
5. Return study questionnaires promptly

Table 1 Treatment Session Content and Homework

### *Hypotheses*

Individuals participating in the FM-REHAB treatment group will have improved (1) symptom management (pain, fatigue, and sleep), (2) self-efficacy for adjustment behaviors, and (3) adjustment at posttest measures compared to the control group. These hypotheses were tested using a two-group (treatment and control) experimental longitudinal study design.

### *Methods*

#### **Procedures**

Following human subjects' approval, a convenience sample of 93 adults with FM were recruited to participate in this pilot study. Study subjects were recruited from a television news report and support groups. Interested individuals called in to the research office. Then all potential subjects

were sent letters inviting them to participate in the research. Informed consent was obtained from subjects who agreed to participate in the pilot study. They were randomly assigned to either treatment or control (mailed questionnaires only) groups following receipt of the informed consent.

The treatment sessions were offered in the form of small treatment groups (less than 8 subjects per group) lead by the primary investigator from 7:00 p.m. until 9:00 p.m. over 4 consecutive weeks. Table 1 details the treatment schedule.

Both treatment and control subjects completed study instruments pretreatment and at four posttreatment intervals (3, 6, 9, and 12 months). All instrument packets were assigned subject numbers to assure subject confidentiality and appropriate tracking of data. The master sheet that matched subjects with numbers was kept in a locked office accessible only to the research team.

### **Sample**

Ninety-three subjects were initially recruited. Due to the statistical analyses used (repeated measures ANOVA), only subjects providing return data at all five measurement periods throughout year 1 were included. The final sample size of 71 subjects represented a 37% attrition rate. The mean pretest scores on all primary variables did not significantly differ between the 38 treatment subjects and the 33 control subjects.

There was no difference in primary variables in those who dropped out of the study. Eight of the control subjects dropped out of the study after discovering that they were assigned to the control group. Another five in the treatment group dropped out because they no longer had symptoms of fibromyalgia. The others were lost due to relocation and our inability to track them.

The sample was 88% female, which represents the preponderance of women who are affected by this disorder. Both groups had a mean age of 51 years (range 15 to 76), degree of disability mean of 5 (range 0–10), and mean number of years with FM was 8.

### **Instruments**

The questionnaires consisted of four instruments used to measure adjustment, self-efficacy, symptom severity, and demographic or FM characteristics.

#### **Self-efficacy for Adjustment Behaviors Scale (SEAB)**

The Self-efficacy for Adjustment Behaviors Scale (SEAB) consists of 26 adjustment behaviors with a 5-point Likert-type response pattern. Content validity is evident in the way items were generated using a review of the literature, expert panels of both patients and nurses, and the expertise of the primary investigator who has multiple sclerosis. Items include adjustment behaviors such as good diet, exercise, communication, knowledge of illness, appropriate medication use, social support, etc. Each item ranged from 1 to 5 with 1 being “No confidence” and 5 being “Total confidence.” A typical item is: I can communicate effectively with my health care provider.

A sample of 256 individuals with multiple sclerosis completed this format of the SEAB in the instrument development study (Wassem, 2000). The Cronbach alpha coefficient of internal

consistency reliability for this sample was 0.91. The SEAB has been used with patients who have either multiple sclerosis, FM, chronic fatigue syndrome, cardiovascular disease, arthritis, or systemic sclerosis with Cronbach alpha levels ranging from 0.88 to 0.93. The Cronbach alpha statistic for internal consistency reliability for the SEAB with the present study was 0.93.

Construct validity was tested by correlating SEAB scores with perceived self-report adjustment items that were significant at a moderate levels: social ( $r = .40$ ), psychologic ( $r = .39$ ), and physical adjustment ( $r = .43$ ).

### **Psychosocial Adjustment to Illness Scale (PAIS-SR).**

An adaptation of the PAIS-SR was used to measure adjustment. The Psychosocial Adjustment to Illness Self-Report Scale (PAIS-SR) has been shown to be a valid, reliable, and objective measure of adjustment to illness (Derogatis, 1986).

The 45-item instrument consists of seven subscales: health care orientation, sexual relationship, extended family relationships, vocational environment, domestic environment, social environment, and psychologic distress.

Due to consistent problems of low reliability levels and missing data that were apparent with two subscales (sexual relationships and extended family relationships), they were eliminated for this study. This dropped the number of items used to 34 items.

Because of the small sample size for the current pilot study, the PAIS-SR was used as a total score. The Cronbach alpha statistic for internal consistency reliability for the total PAIS was 0.93 for the current study. Adjustment was also measured using self-report adjustment items that are covered in the personal inventory description. This allows for multiple measures of this primary dependent variable.

### **Modified Disability Status Scale (MDSS)**

A modified Disability Status Scale (DSS) was developed by the researcher as a measure of the respondent's level of disability. The Kurtzke (1970) Disability Status Scale that has been used as an objective and reproducible method of assessing the degree of disability in individuals with MS.

Modification of the Kurtzke tool was made because only the second part of the instrument that ranks disability levels from 0 (no disability) to 9 (complete bed rest) was used. The first half of the instrument requires a physical exam that was not possible within budgetary constraints.

The subjects were asked to circle the number that best represented their current level of functioning on this single-item measure. As this is a single-item measure of physical functioning, a measure of internal consistency reliability is not appropriate.

### **Adjustment and Symptom Management Scores**

Adjustment scores were measured by circling the number 0 (no adjustment) to 10 (totally adjusted) for each adjustment item (psychologic, social, and physical).

Total adjustment scores are the sum of the three adjustment items with a possible range of 0–30.

Similarly, symptom management scores were obtained by circling the number that best indicates the difficulty they have with pain, fatigue, and sleep using a 10-point measurement from 0 (no difficulty) to 10 (maximum difficulty). The symptom severity score is the sum of these symptom scores with a possible range of 0–30.

### **Personal Inventory**

A personal inventory was designed by the investigator to gather demographic data and information about the subject's illness. Items on the personal inventory were selected for relevance to the study, significance from the review of literature, and review by a panel of experts. Demographic variables in the personal inventory included age, gender, marital status, and length of disability.

### **Data Analysis**

The data were entered into the computer upon receiving the completed mailed surveys. The researcher used the Statistical Package for Social Scientist (SPSS) software package for data analysis and hypothesis testing. All hypotheses were tested at the probability  $< .05$  alpha level of significance.

The analysis of the treatment/control group by time interaction was used to test for significant improvement in the treatment group over the control group. Hypotheses were tested using F statistics from the repeated measures analysis of variance (ANOVA) and analysis of Covariance (ANCOVA) procedure.

### **Results**

Hypothesis 1 stated that the treatment group would have improved adjustment scores at posttest measures compared to the control group. The repeated measures ANOVA for Psychosocial adjustment to illness scale (PAIS) time effect was significant ( $F = 2.39$ ,  $p = .03$ ) and the repeated measures ANCOVA for treatment effect was not significant ( $F = .507$ ,  $p = .36$ ).

This means that the PAIS adjustment scores improved for both groups, but the treatment group did not improve significantly more than the control group for the total sample. Hypothesis one was not supported by the total sample.

We removed those subjects ( $n = 5$ ) from the analysis who had a high level of pretest psychosocial distress (total adjustment  $< 9$ ) following the findings on treatment subgroup patterns by Turk et al. (1998b).

A subanalysis repeated measures ANCOVA that excluded subjects with high pretreatment psychosocial distress demonstrated that the treatment group scored significantly higher PAIS adjustment scores than the control group ( $F = 2.82$ ,  $p = 0.02$ ) which supports Hypothesis 1. Both groups showed some improvement, but the modest improvement in the control group decreased at 9 months, whereas the control treatment group continued their improvement (see Figure 2).

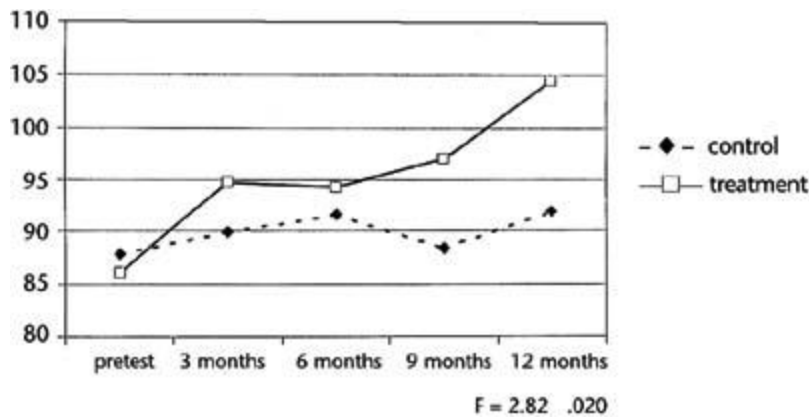


Figure 2 PAIS Scores minus high pretest psychopathology group

Using the self-report scores of perceived social adjustment, psychologic adjustment, and physical adjustment, both psychologic adjustment ( $p = .031$ ) and physical adjustment ( $p = .0015$ ) had significant improvement over time but social adjustment ( $p = .42$ ) did not improve.

Hypothesis 2 stated that control subjects will report higher self-efficacy scores posttest than control subjects. The SEAB scores for the treatment group were significantly higher than the control group at 3 and 6 months, fell off at 9 months, and increased at 12 months. The ANOVA for SEAB time effect was significant ( $F = 5.775$ ,  $p = .0005$ ) but the ANCOVA for the treatment effect was not significant ( $F = .591$ ,  $p = .33$ ). Therefore, Hypothesis 2 was not supported by the total study data nor the subsample analysis.

Hypothesis 3 tested if the FM-REHAB treatment group had better symptom management at posttest measures compared to the control group. Total symptom disruption scores, which consisted of the sum on the three symptom scores (pain, fatigue, and sleep disturbance), were used to test Hypothesis 3. The repeated measures ANCOVA for treatment effect was not statistically significant for the total sample.

Using the subanalysis described in Hypothesis 1, total symptom severity was statistically lower for the treatment group than the control group ( $F = 1.1$ ,  $p = 0.05$ ) providing support for Hypothesis 3 with this subanalysis. Most of this difference was due to improved sleep scores ( $F = 1.34$ ,  $p = 0.031$ ). Maximum treatment effects for pain and fatigue were seen at the 6-month data collection point with regression of symptom control at 9 months and a trend toward improvement at 12 months (see Figures 3 and 4).

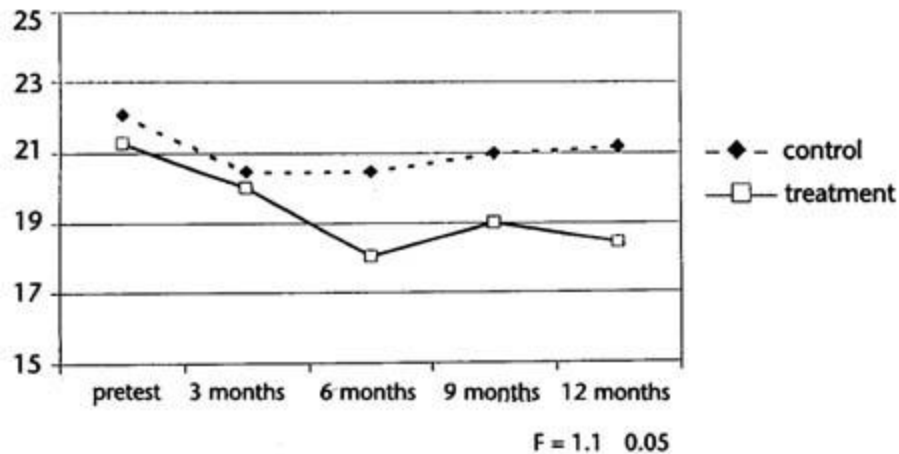


Figure 3 Symptom severity minus high pretest psychopathology group

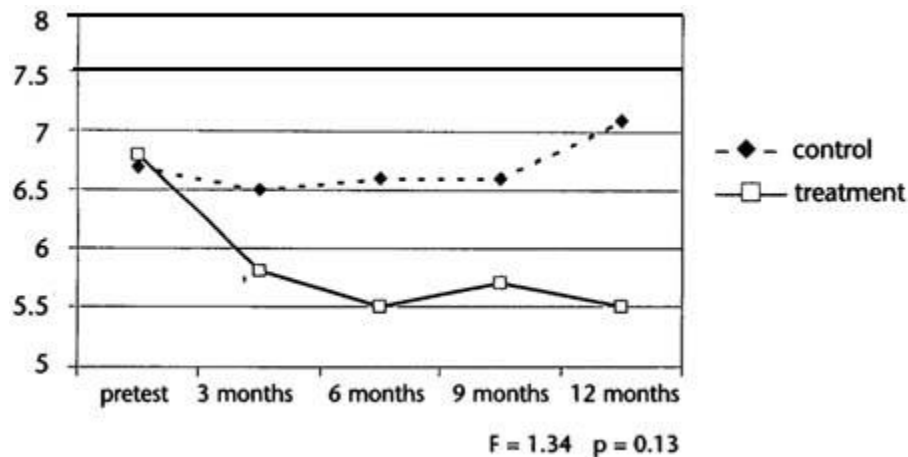


Figure 4 Sleep disturbance minus high pretest psychopathology group

### Discussion

After excluding those with high pretest psychosocial distress, the treatment was effective in improving adjustment in study participants. It is interesting to note that treatment subjects increased their psychologic and physical adjustment more than the control group, but we did not see similar increases in social adjustment.

Many FM patients become socially isolated following loss of jobs and alienation from family and friends. This finding of no improvement in social adjustment provides support for the importance of establishing and maintaining an adequate social support system. It is also consistent with Kenner's (1998) call for holistic treatment plans for FM that include emotional and physical support for both the patient and family.

The treatment program was also successful in reducing symptom severity in study participants. Most of the improvement in symptom severity was due to improved sleep. This is consistent with the belief that sleep disturbance may be the etiology of the problem with FM. The slight increase in symptom distress at the 9-month data collection could be attributed to the busy holiday season with participants doing too many activities or the need for reinforcement of the treatment. It



could also be a real phenomena that requires treatment reinforcement. This provides support for Mason et al.'s (1998) call for addressing relapse prevention.

There was also considerable support for Turk et al.'s (1998b) observation that there are multiple response patterns to interventions for FM. This would suggest that those potential subjects with high pretest psychosocial distress receive psychologic counseling before joining the study. The adjustment and symptom management scores improved after the exclusion of these subjects from the data analysis.

As with any longitudinal study, attrition was a problem. However, the attrition rate for this sample (24%) was less than reports of other studies. Turk et al. (1998A) indicated that they had a 34% attrition rate at 6 months follow-up and Norregard et al. (1997) noted that they had a 40% drop-out rate at 12 weeks. Both of these studies were of considerably shorter duration than the present study. It is likely that completing five measures over a 1-year period may have been difficult for some subjects, or others may have lost interest in participating.

The lack of significant differences in the SEAB scores may have been related to the content of the SEAB. It contains the adjustment behaviors that are taught and practiced in the intervention. Some control subjects started using these behaviors, giving them a weaker mailed form of the intervention, thereby diluting the treatment effect. In fact, some control subjects marked on their surveys that they liked receiving their questionnaires because it reminded them of what they should be doing to control their FM.

#### *Implications for Future Research/Intervention*

In future studies, the SEAB will be administered only to the treatment group to avoid potential contamination of the treatment effect. Alternatively, a three group (group treatment, mailed treatment, and attention) longitudinal study design could be used.

The research team will also exclude those potential subjects with high pre-test psychosocial distress from the study until after they have received psychotherapy and have improved their psychologic status as reported by their therapist. Reinforcement sessions at 6 and 12 months are also planned to improve the maintenance of behavioral change. Further research needs to be done to refine and test this intervention before it can be used with confidence for FM patients.

#### *Implications for Practice*

FM is a chronic illness that is difficult to diagnose and is characterized by multiple symptoms. It takes time and patience to work with FM patients, and there are no quick fixes. Behavior change is necessary in helping them take control of their symptoms.

The article can provide direction in the development of comprehensive nursing interventions for patients with FM and potentially other musculoskeletal chronic illnesses. It provides a framework for behavioral, educational interaction designed to achieve behavioral change to control FM symptoms.

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